



## **EUnetHTA strategy for and initiatives with stakeholder involvement**

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# European network for Health Technology Assessment (EUnetHTA)

## Background

EUnetHTA (2006-08) was a network of 64 partners

The network had representatives of:  
EU Member States, EFTA, EEA and USA, Canada and Australia

The partners represented:

- Regional and national HTA agencies
- Ministries of Health
- University Departments
- International organisations (WHO, OECD, INHATHA and HTAi, Cochrane Collaboration)

The EUnetHTA project continues in the *EUnetHTA Collaboration*

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# Objectives

“A sustainable open EUnetHTA Forum to exchange views, expectations and feedback on HTA with stakeholders”

Specific objectives regarding stakeholders:

“Stakeholder involvement will be encouraged in all work packages.”(8 work packages)

”To support improved responsiveness by building a sustainable open forum for EUnetHTA to exchange views, expectations, and feedback on HTA with HTA stakeholders”

An indicator for progress of stakeholder relations was:

“A sustainable open EUnetHTA Forum with participation of main stakeholders established”

# Definition of stakeholders

Basic questions to consider in relation to stakeholders were:

- 1) who to involve
- 2) how to involve and
- 3) what to involve different stakeholder groups in?

The partners defined Stakeholders as:

*Groups or organizations which potentially will be affected by, or have an interest in and may in a consultative role influence on the actions or aims of an organization, project, or policy direction” (adapted from literature)*

- The focus was on associations and organizations with a stake in HTA at European level
- Organizations are accountable to their members

# Rationale for focusing on stakeholder involvement

The main objective of stakeholder involvement is to ensure representation of interests in and legitimacy of HTA and thereby enhance the possibility of utilizing HTA in policy making.

In studies concerning interest representation, legitimacy, and democratic, political institutions it is suggested that legitimacy rests on “reason giving” \*

Legitimacy concerns the ability to give “reasons for policy decisions that are understood and perceived as sound by those who are to submit to that authority”\*.

\*Humphrey M. Democratic legitimacy, public justification and environmental direct action. Political Studies. 2006;54:310-327.

\*King LA. Deliberation, legitimacy, and multilateral democracy. Governance. 2003;16(1):1-21.

\*Parkinson J.. Legitimacy problems in deliberative democracy. Political Studies. 2003;51:180-196

# Method: Which stakeholders to involve?

The following stakeholder categories were chosen:

- Policymakers at the national/regional level
- Policymakers at the hospital level, in statutory health insurance, or in health maintenance organizations
- Patient organizations
- Healthcare professional organizations, and
- Industry

EUnetHTA partners were not seen as stakeholders as they were already involved in the project.

Activities were oriented towards European organizations, not  
Individuals

# The stakeholder Open Forum website

## Practical activities

The aims of the website was:

- to provide easy access for stakeholders to information from EUnetHTA
- to be a source site for HTA information

The website contained information on:

- ongoing activities such as meetings and conferences
- stakeholders documents on HTA
- syntheses of stakeholder opinions on different topics and
- links to stakeholder position papers and contact information to EUnetHTA.

Debate and exchange of views with stakeholders happened at conferences and meetings, and in some Work Packages

# Proposal for EUnetHTA Collaboration:

## Inviting stakeholder opinions

A task of EUnetHTA was to establish a sustainable network

First draft of the proposal for EUnetTHA Collaboration was presented at the Internet and through direct mails in November 2007 to:

- subscribers to the EUnetHTA e-news
- selected stakeholders and
- international scientific societies/networks (HTAi, INAHTA, ISPOR)

The comments were processed by EUnetHTA Executive Committee and the revised draft went through 2nd round of internal review

2nd round of public consultation on the proposal for EUnetTHA Collaboration was distributed through the Internet and subscribers to the EUnetHTA e-news in March 2008 for all interested including stakeholders

Comments were processed by the Executive Committee and handled by the Steering Committee and adopted in June 2008

# What are dilemmas in stakeholder involvement?

How to obtain a balanced representation of all potential interests?

What to do if industry is overrepresented and patients, medical societies', health care managers' interests hardly represented?

It appears as if stakeholders with funding can be active, those without have difficulties!

What level of agreement between EUnetHTA partners and stakeholders is needed on methodological issues and assessment of quality of studies and data?

How to obtain sharing of data and other information between partners and stakeholders? Mutuality is desirable.

# Meeting with stakeholders to develop policy

For the stakeholder meeting in May 2008: Interest analysis

Number of organizations invited to the meeting and how many participated:

- EU-level policy organization: 1 / 0
- Policymakers at institutional level: 4 / 0
- Patient Organizations: 9 / 1
- Health Care professionals: 4 / 1
- Industry: 9 / 3

In total 27 organizations invited; 5 participated (7 persons) excl. partners

Documents discussed were:

- EUnetHTA Stakeholder Discussion Topic Catalogue
- Draft Stakeholder Policy for EUnetHTA Collaborations

A meeting report included the recommendations for the future policy

# Results: Stakeholder policy at stakeholder meeting

A guiding principle was transparency in work in EUnetHTA, such as:

- Involvement of stakeholders
- Financial issues
- Working methods

For future EUnetHTA Collaboration it was suggested:

- to ensure stakeholder involvement through consultation and discussion
- to be assured through participation in an advisory group
- called Stakeholder Forum
- that the future Stakeholder Forum would communicate with the EUnetHTA Collaboration Executive Committee

Contribution on Stakeholder involvement in future EUnetHTA Collaboration:

- Minutes of the meeting, including
- Policy Document and
- Discussion Topic Catalogue

# Results: Policy for Transparency in financing and work methods

Funding will be accepted from:

- membership fees
- contributions from the EU, governments, publicly funded statutory health insurance organisations and non-for profit organisations
- other sources of funding will need approval from the EUnetHTA Plenary Assembly
- funds must be unrestricted
- disclosure of conflicts of interest is requested

Work methods with stakeholder involvement will be ensured through:

- review and public consultation processes
- meetings with the Stakeholder Forum that represents interest organisations
- involvement of individuals in working groups provided that they:
- participate as individual experts and do not represent stakeholder interest
- cannot constitute the majority in any working group
- disclose conflicts of interest

## What did we learn?

1. It is important to know the interests of stakeholders:  
Involve!                      Be interested!                      Know more!
1. It is important to plan for stakeholder involvement:  
secure time and resources
2. Be precise about who, how and when to involve stakeholders at supranational level (differs from involvement at national level)

# Thank you for listening

This presentation was done on behalf of

- Finn Børlum Kristensen, Project Leader, DACETHA, Denmark
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- Marie Louise Bistrup, Research Assistant, EUnetHTA secretariat, DACEHTA, Denmark

and the WP 6 partners of EUnetHTA project

Please take a look at: [www.eunethta.net](http://www.eunethta.net)